

# :::Your Healthcare



THE NATIONAL WORKING GROUP ON  
EVIDENCE-BASED HEALTH CARE



April 28, 2009

**Your Healthcare:** Who's in the Driver's Seat?  
Evidence-Based Healthcare Regional Forum





## Overview ... [Overview](#)

As the Obama Administration prepares a health reform agenda, patients and consumers have a unique opportunity to steer the future of healthcare decision-making and guide health policymaking. Shortfalls in the value of care delivered have created a system that is more expensive with poor results, ultimately failing to meet the needs of patients and consumers. Evidence-based healthcare, the use of evidence, clinical expertise, and patients' values to make the best decisions about the delivery of care, could be a driving force for improving our healthcare system.

The National Working Group on Evidence-Based Healthcare (the Working Group) is a coalition representing more than 40 consumer, patient, caregiver, and practitioner organizations. The Working Group seeks to ensure that patients and consumers are a part of policymaking about the future of health care. In an effort to raise awareness about evidence-based healthcare, the Working Group wants to mobilize state and local advocates to make sure policy discussions that will influence care decisions consider the preferences and values of patients and consumers. Ultimately, we want to empower local and state advocates to make patient and consumer involvement a priority in evidence-based healthcare.



### **Evidence-Based Healthcare Regional Forum Goal**

To educate state and local advocacy leaders about evidence-based healthcare and its influence on the overall access and delivery of health care. The 2009 Regional Forum will help enable participants to recognize and be conversant in evidence-based healthcare and its influence on healthcare decision-making. Topics covered will include:

- what you should know about evidence-based healthcare,
- why it's key to federal and state healthcare reform discussions,
- how to recognize and be conversant in evidence-based healthcare policy, and
- how to recognize the influence evidence-based healthcare policy has on healthcare decision-making.

### **Audience**

Patient/consumer advocates, providers, and other key health care and policy stakeholders in New England. The target audience includes New England-based affiliates of Working Group member organizations, consumer/ patient advocates and others who are interested in joining in efforts to ensure the appropriate use of evidence in healthcare policy decisions.

### **Approach**

The free one-day (April 28, 2009) forum will feature expert presentations and dialogue-based panels. Participants will 1) learn how evidence-based healthcare and policy impacts patient care; 2) hear from policymakers seeking to use evidence-based healthcare to inform decision-making; and 3) practice getting involved in evidence-based healthcare policy discussions.



## Patient Profile ... PATIENT PROFILE

### Be Informed: What Drives the Medical Decisions for Your Care?

As a child, Robert was diagnosed with epilepsy, a brain disorder that gives him recurrent seizures that affect how he feels or acts for a short period. Robert started taking medications to control his seizures and for nearly 30 years his seizures were limited, predictable, and did not interfere with day-to-day life.

As an adult, his pharmacist switched his usual medication with another (a generic). Not knowing about this switch, Robert started experiencing breakthrough seizures, fainting spells, dizziness, nausea, and personal frustration. His seizures went from 1 or 2 a year to as many as 13 a year. Drug substitution like this is usually a result of comparative effectiveness reviews that find few differences between similar drugs when tested in a large population. However, individuals like Robert may react differently and substantially to each of the medications.

Since Robert's seizures increased and became less predictable, he and his doctor have tried a variety of approaches to improve his day-to-day life, including switching back to his old medication and trying new medications, dosages, and combinations, but each comes with its own benefits and side effects. Yet none of them completely prevents his seizures or is able to help him return to the level of health he experienced before his medication was switched. Robert and his doctor are running out of medications, dosages, and combinations to try. Like countless patients and consumers, Robert is frustrated with the lack of information available on what medication works best for him.

Robert remains hopeful. In the last few years, he has become his own personal advocate – meeting regularly with his doctor, seeking information on different treatment options, and consulting with friends, family, and advocacy groups. His goals are to be free from side effects and remain seizure-free. Robert says, "I want to have treatment that will work for me personally."



# Agenda

## 9:30 a.m.

### Welcome and Opening Remarks

Hazel Moran, Mental Health America

## 9:45 a.m.

### Recounting Patient Experience

Lynn Dann, Epilepsy Foundation

## 10:05 a.m.

### Overview of EBH Trends and How They Drive Patient Care

Reginald Williams, Avalere Health

## 11:05 a.m.

Break

## 11:15 a.m.

### Case Study: How Does EBH Influence Patient Care?

Vivian Weisman, Mental Health America of Rhode Island

## 12:15 p.m.

### Lunch Exchanges

Network and talk about EBH with other local advocates

## 12:45 p.m.

### Roundtable: What Are States Doing?

(starts during lunch)

Paul Jeffrey, Pharmacy Director, Office of Medicaid, Massachusetts - invited

Group Discussion

## 1:45 p.m.

Break

## 1:55 p.m.

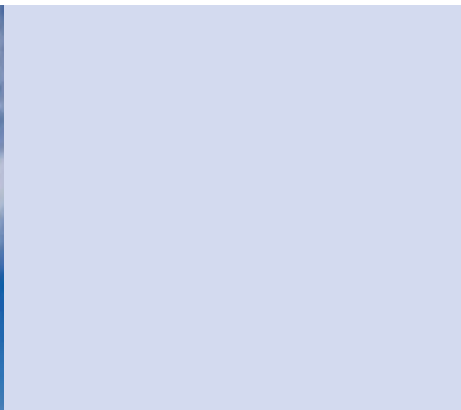
### Preparing for More Local Engagement: What to Do?

Facilitated Role Playing for Getting Involved in EBH

## 3:15 p.m.

### Next Steps: The Working Group as a Resource

Hazel Moran, Mental Health America



April 28, 2009

EBH Regional Forum

Doubletree Hotel

5400 Computer Drive

Westborough, MA 01581

*See back for directions* ↘

# Registration Form

**Registration Deadline: March 20, 2009**

**Will you be attending the EBH Regional Forum?**

**YES**, I will be attending the Forum on April 28, 2009.

**NO**, I am unable to attend the Forum on April 28, 2009.

In order to keep down costs, we ask you to try to arrange travel so you do not need a hotel room. We have very limited funds to reimburse for travel and lodging. Eligibility for reimbursement for a hotel room will be made on a case-by-case basis. For questions about travel, please contact Hazel Moran at [hmoran@mentalhealthamerica.net](mailto:hmoran@mentalhealthamerica.net).

**Are you interested in receiving more information about the Working Group?**

**YES**, I am interested in receiving more information.

**NO**, I am not interested in receiving more information.

NAME: \_\_\_\_\_

ORGANIZATION: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

CITY: \_\_\_\_\_ STATE: \_\_\_\_\_ ZIP: \_\_\_\_\_

PHONE: \_\_\_\_\_ FAX: \_\_\_\_\_ EMAIL: \_\_\_\_\_

**SPECIAL DIETARY NEEDS:**

\_\_\_\_\_  
\_\_\_\_\_

**PLEASE RETURN THIS FORM NO LATER THAN March 20** to Gloria George-Angel via fax at 703.684.5968 at Mental Health America or email this information to her at [ggeorgeangel@mentalhealthamerica.net](mailto:ggeorgeangel@mentalhealthamerica.net)

## Directions to the Hotel



### THE NATIONAL WORKING GROUP ON EVIDENCE-BASED HEALTH CARE

From Worcester: Route 9 East to Computer Drive/Research Drive Exit. Take a right at the first set of lights onto New Flanders Road; bear right onto Computer Drive, head straight through the third set of lights, drive 1/2 miles and the hotel is on the left at the top of the hill.

From Sturbridge: Mass Turnpike (I-90) East to Exit 11A, I-495 North to Exit 23B (Route 9 West) to Computer Drive/Research Drive Exit. Bear right at the end of the ramp, drive 1/2 mile and the hotel is on the left at the top of the hill.

From I-495 North or South: Exit 23B (Route 9 West) to Computer Drive Research Drive Exit, bear right at the end of the ramp. Drive 1/2 mile and the hotel is on the left at the top of the hill.

From Connecticut: Route 84 North to Mass Turnpike (I-90) East to Exit 11A (Route 495), Route 495 North to Exit 23B (Route 9 West) to Computer Drive/Research Drive Exit. Bear right at the end of the ramp, drive 1/2 mile and the hotel is on the left at the top of the hill.

General Edward Lawrence Logan Int'l

Directions: Mass Pike (I-90) West to Exit 11A (Route 495 North). 495 North to Exit 23B (Route 9 West). Route 9 West to Computer Dr./Research Dr. Exit (1st exit off Route 9), bear right at end of exit. Drive 1/2 mile and hotel is on left at top of hill.